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ABSTRACT

Questionnaires were sent to 42 schools in New Jersey to determine the educational procedures used with students having Tourette Syndrome, a neurological condition resulting in body tics and inappropriate vocalization. Parents of an elementary child with the syndrome who was mainstreamed were interviewed and his classroom teacher was also queried about the child's adjustments. Analysis of 26 completed school questionnaires revealed that of 23 students identified as having the syndrome, 11 were mainstreamed, 3 required no special adjustments and 8 were provided with some kind of accommodation. Among other findings were that although symptoms varied among individuals, students with Tourette Syndrome require acceptance from teachers and peers, with limited stress and a de-emphasis on competition. Control medication was found to interfere in some instances with the child's cognitive functioning, and the syndrome was estimated to be linked with learning disabilities in 50% of all cases. (CL)

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MODALITIES OF EDUCATIONAL MANAGEMENT OF THE TOURETTE SYNDROME CHILD

by Renee Price

Advance Seminar
May 1983

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CHAPTER ONE

Tourette syndrome is a neurological disorder of the central nervous system characterized by involuntary gross and fine muscular movements (tics), uncontrollable vocal sounds such as grunting, barking, shouting, coughing or sniffing and the vocalization of inappropriate words usually manifested by echolalia (the senseless repetition of other people's words), palilalia (repeating one's own words) and coprolalia (the involuntary shouting of obscenities). "The illness is referred to as a syndrome because the etiology is unknown and the diagnosis is based on (this) complex of symptoms." (Shapiro et. al., p. 104). Although the condition is lifelong and chronic, Tourette syndrome is not degererative and the life span and intelligence (problem-solving ability) of its victims are consistent with the unaffected population.

The symptoms occur during early childhood and/or adolescense, usually between the ages of 2 and 16 and affect three times as many boys as girls. The symptoms can represent a continuum from the most mild form of a few body tics and subtle vocalizations to the severest form which demonstrates all the symptoms in their greatest intensity.

"Once listed under 'exotic diseases' in medical school texts, Tourette syndrome was virtually ignored by the medical community until about 10 years ago." (Mehren, L. A. Times). Today research suggests

viable evidence that this illness affects up to "100,000 people in the United States. Maybe more." (Sullivan, Daily News).

Because the symptomatology of Tourette syndrome is usually viewed by people as bizarre, disruptive and frightening, it usually provokes ridicule, distain and rejection causing severe feelings of shame and humiliation in its victims. Tourette children in school are especially discriminated against by their peer group because their behavior is so incomprehensible to their classmates; and to most children and adolescents, being different is anathema.

In addition to suffering this social isolation, "investigators believe that more than half of Tourette patients sustain some degree of minimal brain dysfunction. Children with minimal brain dysfunction have a normal range of intelligence, but their short attention span, low frustration tolerance, hyperactivity, poor coordination and specific areas of learning disability make it probable that they need special attention in school." (Tourette Syndrome Fact Sheet). Adjustments must also be made for psychological problems that may result as a consequence of Tourette syndrome, as they could also greatly interfere with a child's social and academic progress.

With the assistance of the Tourette Syndrome Association, whose national headquarters is in New York City, this writer learned that there is more than just an isolated incidence of Tourette syndrome in New Jersey. The purpose of this paper is to investigate the educational settings

provided by some of the special education departments of the various school districts where there is an incidence of Tourette syndrome. A case study of a Tourette child and his parent's struggle for his correct academic placement will also be presented concommitant with the results of an interview with one of this child's teachers.

This is not an epidemiological, demographic or statistical approach to the problem of Tourette syndrome. It is an informational study, designed only to investigate how some school districts that experience Tourette syndrome victims provide an appropriate education for them.

The importance of this study, although limited in scope by its definition, is two-fold: (1) - to help publicize the plight of the Tourette child and his family to educators and (2) - to try to discover if he or she is receiving the free and appropriate education entitled them by law.

CHAPTER TWO

Although the exact idiology of Tourette syndrome is not known, "it is thought to be caused by a chemical abnormality in the neurotransmitter system by which the brain regulates movement and behavior. Neurotransmitters are chemicals that carry signals from cell to cell in the brain along the nerves." (Tourette Syndrome Fact Sheet).

The first evidence that documents Tourette syndrome came in 1825 when Dr. J. M. C. Itard, a French physician, described the case of a young French noblewoman who, since the age of seven, had suffered from involuntary muscular tics later accompanied by coprolalia. In 1885, another French physician, Gilles de La Tourette, reviewed her case and clinically documented eight more. Ever since then, the disorder has borne his name.

Until the efforts of Dr. Arthur K. Shapiro, now clinical professor of psychiatry at Mt. Sinai School of Medicine in New York City, some 30 years ago, the syndrome was nearly forgotten by the medical community. As a result of his experiences with Tourette sufferers while a medical student and later as a practicing psychiatrist, Dr. Shapiro's interest in Tourette syndrome burgeoned. His wife, Dr. Elaine Shapiro, a psychologist on the staff of Mt. Sinai Hospital in New York City, joined him in his research and study. They and other contributors published the results of their investigations in a book, Gilles de La Tourette Syndrone,

in 1978. Since then interest in the syndrome has mushroomed.

Recent studies indicate the possibility of genetic causes. "A high incidence of previous tics in the family has been discovered among Tourette patients. Also, an unusually high percentage of patients, as many as half, are of Eastern European background, mostly Jewish. Correspondence with doctors abroad has revealed very few black Africans who have the syndrome, and a large number of people in Israel who do." (Sullivan, the Daily News).

There is yet no known cure for this malady. It is presently treated chemically with drugs. Most successful repression, but not complete, of the symptoms is caused by the tranquilizing drug, haloperidol. The trade name is Haldol. The drug, however, produces short term side effects such as muscular rigidity, drooling and restlessness. Artane and Cogetin, drugs commonly used to treat Parkinson's disease, can relieve these symptoms. Other side effects of haloperidol such as fatigue, depression, anxiety, weight gain and difficulties in cognitive thinking can only be alleviated by complete withdrawal from the drug. Haloperidol is given in small doses and increased slowly until the best possible balance between symptom and side effect is achieved. However, because of the continual waning, waxing and shifting of symptoms, and the complexities of the side effects of all the drugs involved to treat the symptoms, controlling the syndrome can be an arduous and time consuming task. Consequently, complete suppression is rare.

Tourette syndrone is a multiple tic disorder. Although a handful of cases have been reported where there has been complete remission of symptoms after adolescence, this non-degenerative illness is chronic and lifelong. Its symptoms may display themselves in varying degrees of intensity, from simple facial twitches to an explosive demonstration of them all. Some Tourette children are learning disabled and some are not. "Effects of Tourette syndrome upon cognitive functioning may vary greatly between children and with the individual child over time." (Wertheim p. 17). The tics may have an indirect effect as the learner attempts to inhibit symptoms in the classroom. This rush of concentration can distract from the effort needed to learn the task at hand and usually causes an eruption of other explosive symptoms. The effects of medication can blunt the cognitive processes and medication rarely results in complete suppression of symptoms.

Tourette syndrome is an umbrella of symptoms; its victims bound by its common veins; yet each individual can exhibit different symptoms at his own particular developmental and/or cognitive stage of growth.

Therefore, one can assume that there is no one elixir educationally. Individual adjustments should be made for individual needs and educational nostrums should be consistent with these needs. There will probably, however, be "umbrella" statements: Guidelines for the education of children with Tourette syndrome that will surface as a natural and common-sense approach to this problem.

CHAPTER THREE

Although exact demographic information that would pinpoint the occurrence of Tourette syndrome in New Jersey was not available, conversations with the presidents of the various local chapters of the Tourette Syndrome Association throughout the state revealed that the largest and most active chapters were in the Bergen, Essex, Hudson, Middlesex, Morris, Somerset and Union County areas. Therefore, questionnaires regarding educational procedures were sent to some of the larger school districts in these areas with the assumption that (1) - Tourette victims would indeed be found in these areas, (2) - that the school districts contacted would reply and (3) - that the replies would accurately reflect their situations. The cover letter included with the questionnaire stressed its purpose and also the complete anonymity of quest and reply.

Anonymity was also the issue in presenting the case study of a Tourette child and his parent's struggle to obtain the proper educational placement for him. The facts of this case were obtained through a personal interview by this writer with the child's mother and one of his classroom teachers. All are residents of a local New Jersey township, and this incident occurred in that town's school district.

The results of the interview with the teacher concerning her experiences with the child in her classroom are also recounted in this paper.

Although the teacher had no objection to the use of her name, it was

decided that it not be used out of deference to the child's parents. They granted permission for their child's story to be documented, but wished all links to his identity destroyed.

Therefore, in recounting the facts of these interviews, the alias, "John", will be used to identify the child and "Mrs. Smith", the teacher.

Format for Parental Interview

There was no formal format for this interview. John's mother was asked to start his story beginning with an official diagnosis of his condition and relate only those experiences having to do with his school career.

Format for Teacher Interview

(1) How much in advance did you learn of John's entrance to your class?

(2) Were you given any information regarding his symptoms? That is, what to expect of him or the severity of his symptoms.

(3) Were you given any guidelines for how to manage or interpret John's behavior in your classroom?

(4) Did you make John's classmates aware of his condition and consequently of what to expect?

(5) Did you find his behavior extremely disruptive?

(6) Did it annoy you?

(7) Did it annoy his classmates?

(8) How was he regarded by his peers? Was he accepted, rejected or ridiculed?

(9) Did you feel his symptoms interfered with his learning?

(10) Were any special adjustments made for John? For example: shortening his written assignments; permitting him a greater degree of physical activity than granted the other children; allowing him access to a private area to display the symptoms; etc.

(11) Did you feel his placement in your class was academically correct?

(12) Did you feel John was happy in your classroom?

Cover Letter for Questionnaire

February 20, 1983

Dear Sir:

In order to complete the requirements for a Master's thesis, I am preparing an informational study on the possible modalities of educational management of the Tourette syndrome child,

This is not a statistical or epidemiological study. It is simply informational. The schools and school districts being polled are those where Tourette syndrome is thought to exist. No method has been devised to tabulate individual responses; therefore, all information will be anonymous. Names are not solicited nor wanted; only the special methods, if any, provided these children.

I would, therefore, be most appreciative if you would take a moment to complete the brief questionnaire enclosed, and return it to me in the stamped, self-addressed envelope provided.

Again, I stress the anonymity of this questionnaire. I seek only suggestions as to the proper management of Tourette children. If you have had any dealings with these children, your experience would be greatly appreciated.

Very truly yours,

Renee Price

QUESTIONNAIRE

(1) Have you had, or do you have, any Tourette syndrome children in your school (district)?

- yes ____ how many ____
- no ____

(2) How was the case diagnosed?

- disclosure by parents ____
- diagnosis by school physician ____
- other (please comment) _____

(3) Was (is) the child (children) mainstreamed?

- yes ____
- no ____

(4) If services were necessary, please check the appropriate option.

( )mainstreamed with minimal supplemental instruction (1 to 5 hours weekly)

( )mainstreamed with maximum supplemental instruction (resource room)

( )classified classroom (N.I. or P.I.) with mainstreaming for non-academic courses

( )total self-contained classroom

(5) Whether mainstreamed or classified, were (are) any special adjustments made for the child (children)?

- modifying time limits ____
- shortening written or oral homework or classroom assignments ____
- provision of private area for child to display symptoms if too intense to contain ____
- allowing opportunities for greater degree of physical movement than usually permitted other students ____
- other(please explain) _____

(6) Were (are) the child's classroom teachers made aware of his symptoms?

- yes ____
- no ____

(7) Was an explanation of the child's behavior given to his classmates?

- yes ____
- no ____

(8) Was (is) the child accepted or rejected by his classmates?

- yes ____
- no ____

(9) Do you feel that the child (children) is comfortable in his classroom placement?

- yes ____
- no ____

CHAPTER FOUR

Results of Parental Interview (Case Study)

When John was in second grade, he was diagnosed by a physician with expertise in Tourette syndrome as having that malady. In fourth grade when behavorial problems started to develop in the classroom, he was reevaluated by a psychologist also an expert in Tourette syndrome. The original diagnosis was confirmed, and it was concluded that over medication on Haldol, causing cognitive problems, was the reason for John's unacceptable classroom behavior. Both of these evaluations were at the expense of John's parents.

Immediately after this, John's elementary school principal decided that he have another evaluation, this time by the school's child-study team. The team classified him as Neurologically Impaired and wanted him placed in a self-contained classroom. As this classification required busing to another school in the district, John's parents opposed the placement. They wanted supplemental instruction for him in the neighborhood school he was presently attending. The team would not agree. The disagreement continued to the end of fourth grade with no resolution in sight and a deteriorating classroom situation for John.

At the beginning of fifth grade, John's parents requested an administrative review of the case. Pending its outcome, John remained in the regular classroom with no written IEP, as compromise between

team and parents could not be obtained. Participating at the hearing were John's parents, the coordinator of special services for the district and their respective lawyers. The school district informed John's parents that he would be suspended from school for any disruptive behavior if their recommendation for a self-contained placement was not heeded. The parents refused to accept this recommendation, and again no compromise was reached at this hearing, which was non-binding in its authority.

John's case was then heard by the Classifications Officer of the state. The psychologist who evaluated John in fourth grade was called upon to testify. A new ruling was declared: John was now identified as Perceptually Impaired and was temporarily to remain in the regular fifth grade classroom, assisted by an instructional aide to help not only with his academic progress, but also to ensure, if possible, that his behavior would be appropriate. John was also to receive all special and support services available.

During this time, John was again evaluated by a psychologist expert in Tourette syndrome. This time the school district paid for the evaluation. The results of testing showed John's I.Q. to be in the upper eighties. However, the psychologist cautioned that this should not be taken as a true measure of John's ability due to interference from Tourette's and medication.

Sixth grade was particularly tumultuous for John. He was taken off

Haldol and Cogetin and tried on a new drug, Clonodine. Tics and acting out behavior were more frequent. An instructional aide was not hired for him initially. However, later in the year, this decision was reversed. Also, all school staff members were asked to keep anecdotal records of John's behavior. During this time, the State Classifications' Officer who originally reviewed John's case reversed his earlier decision and reclassified him as Neurologically Impaired. He was again recommended for placement in a self-contained classroom and if this recommendation was not followed in 15 days, local school officials had the right to expel John from the district.

John's parents appealed this decision to the Commissioner of Education. He moved that John be allowed to remain in his present classroom pending further testimony from both sides. None, however was offered, as during the sixth year John showed remarkable improvement in his behavior. His new medication seemed to reverse itself causing positive effects. Consequently, his elementary school principal recommended him for regular instruction at the junior high school with some support from the resource room. The child-study team reaffirmed this recommendation.

John entered seventh grade as a mainstreamed student with support from the resource room in reading and performed well. Two months later, John's parents received a copy of a letter sent to their lawyer from the Assistant Commissioner of Education stating that since both parents and district were satisfied with John's present educational placement, the situation would remain status quo and all claims against John by the

district would be dropped. At this time, an IEP was also written for John outlining a very definitive program of study with guidelines for interpreting and modifying his behavior.

John is now in eighth grade and completely mainstreamed. At the last report, he is doing well. When, at this point in the interview, John's mother was asked to define "doing well", she replied that academically his grades were mostly A's and B's and an occassional C and that his behavior was now acceptable. Academics, however, she elaborated, was never really the problem. It was John's behavior that was not acceptable. When questioned further as to what was not acceptable about John's behavior, that which was a direct result of Tourette syndrome, or his acting out behavior, she found it difficult to differentiate between the two. It was really not clear to her, and apparently the school personnel, where one left off and the other began. She also suggested that Tourette's symptoms might have provoked acting out type or inappropriate behavior.

Presently, however, John's symptoms are not intense or explosive. He still experiences body tics and subtle vocalizations that do attract attention, but there have been no reports from his teachers of distraction or annoyance to other students.

Results of Interview with Classroom Teacher

Mrs. Smith had no prior notice of John's entrance to her class. Everyone "arrived" together on the first day of school. She did, however, find pamphlets in her mailbox describing Tourette syndrome, but John was identified to her as a Tourette sufferer only at the first meeting of her class. She was given no guidelines to follow in regard to managing or interpreting his behavior.

Mrs. Smith did not mention John's condition to his classmates. She did not prepare them because she, herself, was not prepared. Later on, however, she did not think it necessary, as John seemed to be basically in charge of himself. He seemed to be generally accepted by his classmates except for the Tourette episodes. At these times, he was jeered and/or ridiculed. At other times when he demonstrated inappropriate classroom behavior, he was basically ignored by his classmates and considered a "pest". Unacceptable behavior was not uncommon in Mrs. Smith's classroom and, consequently, familiar to and accepted by the students. Therefore, she felt it unfair to stigmatize or "separate" John from his peers by explaining his problem to them.

Mrs. Smith did not find John's Tourette's behavior disruptive. She did, however, find that it distracted the other students and was annoying to them. She, herself, was not annoyed by John's behavior. She did, however, confess to feelings of anxiety as the Tourette's episodes did

rovoke her other students to torment John. Witnessing these episodes was distasteful to her, as well as stressful to John. However, everyone was quickly able to be redirected to the task at hand and the Tourette's incidents forgotten, once terminated.

Mrs. Smith felt John's placement in her class was academically correct, as he required organizational and integrational skills in reading. She did not feel that his symptoms greatly interfered with his learning and, therefore, no special adjustments were made for him. Those adjustments that were made catered to his perceptual disabilities, like any other perceptually impaired child, and not to his Tourette's symptoms.

Mrs. Smith, who later became cognizant of John's past turbulent school career, suggested that no extra adjustments were made for him because by the time he entered her class he had a good handle on cognitive tasks and was in control of his symptoms. She also felt that for the most part, John was relaxed in her class and not terribly troubled by feelings of anxiety after a display of symptoms. He appeared to be content.

Results of Questionnaire

In compliance with the promise of anonymity, no method was devised to tabulate the individual responses of the schools and school districts contacted. All information is, therefore, reported as the holistic results of the questionnaire.

Forty questionnaires were sent to school districts in Bergen, Essex, Hudson, Middlesex, Morris, Somerset and Union Counties. Two private schools in Middlesex County were also contacted. A listing of the school districts by county is as follows:

Bergen County

Bergen County Special Services District
Bergenfield
East Rutherford
Fairlawn
Hackensack
Paramus
Ridgewood Village
Teaneck
Tenafly
Westwood Regional School District

Essex County

East Orange
Livingston
Millburn Township
Montclair
Orange City
South Orange-Maplewood
West Orange

Hudson County

Jersey City

Middlesex County

East Brunswick
Edison
Highland Park
New Brunswick
Piscataway Township
South Brunswick Township
Old Bridge Township
Woodbridge Township

Morris County

Morris County Educational Services Commission
Morris School District
Parsippany-Troy Hills Township
Rockaway Township

Somerset County

Franklin Township
Hillsborough Township

Union County

Elizabeth
Linden
Plainfield
Scotch Plains-Fanwood
Summit City
Union Township

The two private schools polled were the Pesach Raymond Yeshiva in Edison and the Solomon Schechter Day School in East Brunswick.

Of the 40 questionnaires sent, 26 responses were received. Twelve of the 26 respondents reported no cases of Tourette syndrome. There were 23 Tourette victims reported among the 14 remaining respondents. Although the questionnaires were not coded as to the exact locations to which they were sent, postmarks indicate that the densest Tourette population is in Middlesex County and the North Jersey area: the former reporting eight cases and the latter reporting 11 cases. Questionnaires with postmarks from Trenton, Linden and Scotch Plains reported one case each in the latter cities and two cases in the former. One case was diagnosed by a school pediatric neurologist. Eleven cases were diagnosed by disclosure from parents and confirmation by medical personnel, and 11 cases reported disclosure by parents as the source of diagnosis. Eleven children are mainstreamed. Three of them require no special adjustments. The remaining eight are provided with one or more, or all of the special adjustments listed on the questionnaire. On the questionnaire from a school district in Trenton reporting two cases, one mainstreamed and the other in a classroom for neurologically impaired children, "additional

positive reinforcement for accomplishments" was added as a special provision.

Of the 12 remaining cases, four are in total self-contained classrooms, six are classified as neurologically impaired but mainstreamed for non-academic courses and two are in a resource room. All of these children are also provided with one or more of the special adjustments listed on the questionnaire. In a school district in Middlesex County reporting two Tourette sufferers, both in a neurologically impaired classroom, additional special provisions noted are "school physician supervised - medical intervention with psychiatrist".

In every instance, the classroom teacher was made aware of the child's condition. In three cases, the child's classmates were informed of the problem. In the remaining 20 cases, no disclosure was made to peers. Thirteen children were reported as being accepted by their classmates with two cases reporting qualifying circumstances. One district in Middlesex County, reporting three Tourette children, found this a difficult judgement to make. The remaining seven children are, or were not, accepted by their peers. On the questionnaire from a school district in Middlesex County, reporting two cases of Tourette's in which one child was accepted and the other is not, the comment in regard to peer acceptance reads "pupil is rejected by peers, parents, and staff".

Eleven respondents felt their children were or are comfortable in their present classroom; one felt that it was difficult to make this

determination, and two felt that their children are and were not happy in their classroom situations. The following positive comment appeared on the back of a questionnaire received from a North Jersey school district with one Tourette child: "The individual student we have dealt with is unique in many respects. He has extremely poor fine motor coordination, but is an extremely bright, outgoing student. He was treated with medication in the past. The medication became counter-productive, and he went through a difficult time while the medication was gradually eliminated. During that time, he was in a self-contained NI class. He is currently mainstreamed with supplemental instruction and doing well. The family has sought the services of the local Family Service and Child Guidance Clinic. The student has been placed with very patient teachers who have positive feelings for him. The school which he attends is small (under 200 students), and staff members tend to know and support all students. The family has also sought excellent medical guidance through Yale University. Yale University added to our knowledge of this child and aided the family in their understanding. Adaptive Physical Education was an ingredient which in helping this boy learn to ride a bicycle, offered a tremendous boast to his self-esteem and contributed greatly to improved peer relationships."

CHAPTER FIVE

There are certain limitations that must be imposed on the results of this study before any meanings can be discussed or knowledge extrapolated.

First, one must depend upon the integrity and accuracy of recall and response of those individuals polled, as they represent the sources of data for this study.

Secondly, since their number is so small, conclusions should be generalized to this immediate situation. However, if one assumes that other populations, similar in circumstance to the one sampled, are like the one sampled, then greater generalizations can be inferred.

Regarding the immediate situation: In order to persuade individuals to participate in this study, much assurance had to be given them that all measures would be taken to ensure their anonymity. John's mother permitted his story to be documented but without revealing his identity or those of the individuals involved. Preliminary and informal discussions with school officials experiencing Tourette's cases indicated a reluctance to have their particular situations documented. Therefore, if anonymity of response was not promised the schools and districts polled, it is doubtful they would have responded at all. This desire for confidentiality in both instances could be for different reasons: In case of the sufferer, to avoid the stigma of a humiliating disease; in case of the schools, perhaps to

avoid an uncomfortable situation; not knowing precisely how to deal with this malady.

The confusion and inconsistency on the part of well-meaning educators as to how to deal with Tourette's syndrome in the classroom is exemplified in John's story. In his particular case, it is difficult to decide who resolved what. As John's symptoms became less obvious, his situation improved. Had his symptoms continued to be unacceptable in the classroom, how would educators have provided him with an appropriate education that would be satisfactory to him and his parents and yet not impose upon his classmates?

If John's case can be likened to that of other Tourette sufferers with similar symptoms, then one can conclude that Tourette syndrome is indeed a debasing and humiliating disease for the sufferer, and can be a perplexing enigma for well-meaning educators who must fulfill their responsibility to disabled children without infringing upon the rights and needs of able children.

Since all Tourette's victims share some common symptoms in various degrees of intensity, then the generalizations inferred from the responses to the questionnaire sent to a few local school systems and the facts of the case study can serve as basic guidelines for the education of all children suffering from Tourette syndrome.

Although all Tourette victims share common symptoms, they vary among individuals, as well as in each individual, as to intensity and number

at any given time. The symptoms may wax, wane and shift within each individual, as well as among individuals. Therefore, in every situation, the individual needs merit individual solutions. However, the very physiology and psychology of this disease demands these basic considerations be heeded:

> All Tourette students require a tolerant and benign setting in order to reach their full academic potential. "We soon learned how vital an excellent school situation is... Sean's kindergarten teacher had been ideal for him, calm, reassuring, well organized and intelligent with a good sense of humour . . . In first grade, however, we experienced an unfavorable school setting. The teacher was strict, rigid, tense, disorganized and assigned a great deal of repetitive, boring work." (Harmon, p. 105). All school personnel, especially the classroom teacher, should be made aware of not only the symptoms of the disease, but also of the shame and social isolation a Tourette child usually suffers. They should be encouraged to be accepting and patient. Discretion should be used as to whether classmates be informed of the Tourette child's condition. Being different is usually anathema to most children and adolescents; therefore, acceptance of the child by his classmates should be encouraged by everyone.

"In general, stress exacerbates symptoms. The effects of stress must, therefore, be considered in all learning settings." (Wertheim. p. 21). Individual growth in academics and sports

should be stressed, rather than competition with others for success in these areas. Time limits, another source of stress, should also be modified, as symptoms can and usually do interfere with cognitive functioning, especially in tasks like handwriting and typing.

Even if they are relatively symptom free, most Tourette children experience restlessness, probably from trying to suppress their symptoms and, therefore, need the opportunity for more physical movement than usually permitted other children.

If and when symptoms become intense, a refuge should be made available where the expression of a tic or vocalization will not be noticed by other people. Some private area like a nurse's office is an important need in the educational planning of Tourette children.

Caution should also be used in interpreting scores of I.Q. and standardized tests as symptoms and medication can and usually do interfere with performance.

CHAPTER SIX

Tourette syndrome is a debasing and humiliating disorder of the central nervous system. It causes behavior in its victims that is bizarre and incomprehensible to onlookers. As a result, most sufferers, especially children, bear the scorn and ridicule of the public and consequently experience social isolation.

Current statistics indicate 100,000 Americans diagnosed with this malady with many more cases being uncovered continually. The disease is lifelong and chronic, and affects three times as many males as females. Fifty percent of those afflicted sustain learning disabilities.

Because the tormenting symptoms, which comprise the disease, and the medication necessary to control them, can and usually do interfere with cognitive functioning, many Tourette syndrome children require special educational settings so that they can learn to their optimum potential.

Based upon prior investigation, an assumption that the syndrome was present in various New Jersey schools and districts was made. A questionnaire was sent to those schools and districts requesting information on their handling of Tourette children, if indeed they experienced them. Complete confidentiality of reply was assured. Also with the promise of complete confidentiality, personal interviews with the parent and a teacher of a Tourette child were obtained. The results of both the replies to the questionnaire and interviews were documented and interpreted.

Although this sampling was very small, it is assumed that generalizations inferred from these particular situations are applicable to a greater similar populous because all Tourette sufferers endure most of the same symptoms to a greater or lesser extent, and all onlookers probably share the same attitudes about them.

As the need for anonymity of source became a prerequisite for obtaining information, one can conclude that Tourette syndrome is indeed a humiliating and debasing disease, and one that is not comfortably discussed by anyone involved with it.

The cumulative results of the replies to the questionnaire and the facts from the case study and interview with the teacher seem supportive of the original hypothesis: Although all Tourette sufferers share the same symptoms, they can be different in number and intensity within the individual and among individuals. Therefore, every individual case demands individual solutions. However, basic considerations are applicable to all Tourette children in preparing a sound educational setting for them: (1) - Support and acceptance from teacher and classmates are essential for academic growth and social adjustment; (2) - As stress exacerbates symptoms, one should try to eliminate it in all learning settings; (3) - Time limits, themselves a source of stress, should be modified, as Tourette symptoms can and usually do interfere with cognitive functioning; (4) - The energy needed to suppress symptoms can cause a great deal of restlessness. Therefore, Tourette children need more freedom of movement, perhaps more than usually permitted other

children; (5) - A nearby private area should be available if and when symptoms become intensified. There, when they no longer can be suppressed, they can be released without annoying anyone or attracting attention and (6) - The results of I.Q. and standardized tests should not be considered an absolute measure of potential, as symptoms and medication can and usually do interfere with performance.

B I B L I O G R A P H Y

BOOKS

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